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Photos by Clerc Center staff

inclusion at a school for the deaf: making it work for a student with special needs

By Bob Brehm

A young boy sits hunched over his math papers in the classroom. He works vigorously, writing carefully and then erasing hard when he makes a mistake. His feet kick the table legs continuously, and occasionally he goes into a self-stimulation mode with a sudden jerking of his head and arms and a vocalization to match his movements. Still, he keeps at the work, seemingly in his own world.

Minutes later the boy looks up and tells his support aide that he's tired and wants her to finish the paper or at least tell him what to write. She patiently yet firmly explains that this is his math work and she'll help when he's stuck, but that he's expected to do the work himself like all the other students in the class. The boy's opposition grows and his self-regulation seems to be depleting. The aide offers him something to satisfy his basic sensory needs, in this case a rubber stretchy toy, which the boy grabs and starts to bite while saying over and over again, "ME TIRED. YOU FINISH." The aide tells him to take a break, and then she reviews the morning schedule with him. In a manner that clearly shows her emotional commitment to working with him, laying out the steps on her fingers, she asks him, "MATH FINISHED. NEXT WHAT?" He correctly answers, "RECESS." Before she can finish reinforcing the expectation that he must do his math work before going out to recess, he pulls himself together, says, "CALM ME," and then gets back to work.

Ten minutes later, math work done and turned in to the smiling teacher, the aide accompanies the boy to the playground for recess. There he wants to play with the other children, but they seem to be communicating with each other and playing at a level he doesn't really understand. So he tries—hard—to join in, but the others become frustrated when he doesn't understand the rules, plays too aggressively, or tries to get them to join his play, which

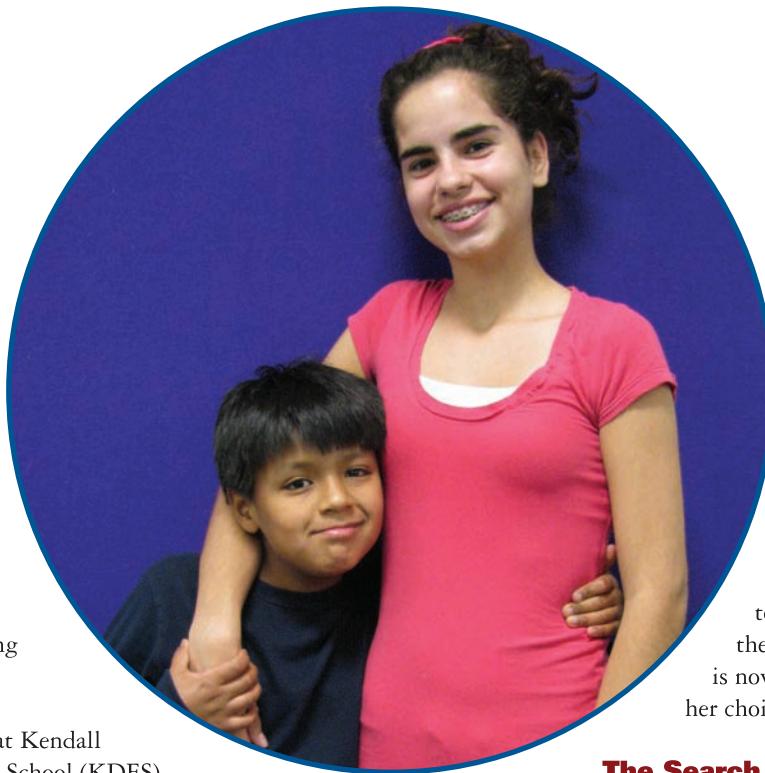


tends to be scripted and repetitive. He finds himself lagging behind the others, sometimes alone and sometimes just on the outskirts of their game. At times the aide is able to successfully engage one or two other children in facilitated play with the boy and all enjoy it. In general, though, his differences lead to him being alone in a group activity.

The boy in this story is a student in the third grade at Kendall Demonstration Elementary School (KDES) on the campus of Gallaudet University, and he is my son. Miguel has a diagnosis of Pervasive Developmental Disorder, or PDD, which along with the more common forms of autism is characterized by significant developmental delays and challenges in relating to others, learning and using language, and sensory processing. His overall developmental profile suggests that he functions more like a 5 year old than like his 9 chronological years. This is Miguel's seventh year at KDES, and we and the school have worked hard over those years to figure

out how to meet his educational needs in a school that does not have a particular focus on students with multiple disabilities.

Miguel was adopted at age 2 from an orphanage in Ecuador, where he had no exposure to sign language and, given his disability, very limited interactions with others. We didn't know about the PDD at the time, believing that like so many adopted



Left: Miguel and his sister, Wendy, share a special moment.

deaf children what he needed most was a loving family and immersion in American Sign Language (ASL). Our family is a mix of hearing parents who sign but are not fully fluent; Miguel; and biological daughter Wendy, who is four years older than Miguel. Wendy is deaf, having begun to lose her hearing at age 2½. We moved to Washington, D.C., to enroll the two children in KDES. Wendy is now an eighth grader focusing on her choice of high schools.

The Search for Reasons

When Miguel's development and language use did not show progress after a year at KDES, we became concerned and sought help. He was very difficult to deal with, showing almost no affection and having frequent tantrums and difficulty sleeping. We received the diagnoses of Attention Deficit Hyperactivity Disorder and mental retardation, both of which we rejected based on our own instincts and those of professionals we consulted who work with deaf children. After an extensive search we found ourselves at the door of Dr. Annie Steinberg, who is a psychiatrist and pediatrician who signs and whose career has focused on the needs of children with behavioral and developmental challenges who are also deaf. With reports from school and videotapes from home as background, she then evaluated Miguel and met with us for a full day. The diagnosis was clear: Miguel has a significant disability.

Dr. Steinberg's suggestions for how to proceed were initially as unsettling as the diagnosis. She steered us to the work of Drs. Stanley Greenspan and Serena Weider and what is known as the Developmental, Individual Differences, Relationship-based Approach, or DIR®. In this approach, the goal is "to build healthy foundations for social, emotional, and intellectual capacities rather than focusing on skills and isolated behaviors" (www.flooritme.org). As this is a highly individualized program designed to engage the child in meaningful shared and emotionally infused interactions, parents are the most important people in the mix, particularly in the early stages. For Miguel to begin to develop in socialization and language, my wife and I would have to take the lead. Their play-based approach is known as Floortime™, and using this model we developed play that allowed for shared problem solving, a continuous stream of interactions, and communication based on facial expressions, gesture, and language to get our little guy to come out of his shell, communicate with us, and enjoy the back and forth of human interaction.





We were amazed at the results. Within weeks of starting that approach, Miguel was calmer, less withdrawn, and more interested in conversation. He was becoming happier and more affectionate every week. Still, we faced the significant challenge of incorporating this approach at school so that Miguel would be similarly engaged there and have the chance to benefit from the talented staff and the ASL-rich KDES environment. After all, we could get him rockin' and rollin' at home, but as non-native signers we could never serve as Miguel's language models or educators.

Collaboration Pays Off

At first it was a challenge getting the people at school to incorporate the DIR approach into Miguel's education. However, we felt it was consistent with what we saw in use at KDES, most notably with the Reggio Emilia approach to early childhood education. Reggio Emilia focuses on motivating each individual child for learning and socialization. Over time, the staff at KDES came to agree that we had to:

- start from where Miguel was at developmentally and go from there, and
- focus on his level of sensory regulation and engagement with others as goals, seeing those as prerequisites for learning and developing in a school environment.

At one point the school's leadership told us that Miguel would be better served at a school that focused on students with multiple disabilities. We explored that possibility, visiting both schools for hearing students and schools for the deaf with a special education or autism focus. In the end we were convinced

that inclusion at KDES was the best option for Miguel. There he receives full immersion in an ASL-rich environment modeling and interacting with typically developing deaf peers. We told the school our preference was to stay, but that Miguel would need accommodations to make that happen. We believed that given KDES's mandate and small size, it would be possible to get Miguel the resources he needs to succeed. After much negotiation, we were relieved to learn that the school agreed.

An Educator and Accommodations Make a Difference

We worked with the school to identify the support Miguel needed. Perhaps the most significant of the resources that has been offered to Miguel has been the 1:1 aide assigned to him. Charity Warn, now a KDES math teacher, was assigned to work directly with Miguel for two years. Her role was to keep him engaged—with her and with others as much as possible. She

was also to make sure he got breaks both inside and out of the classroom and that he was prepared for transitions throughout his day. With her warmth and expressive signing, Charity took Miguel places in conversation that we'd never seen before. For the first time, people at school were seeing the joyful Miguel that we had come to expect all the time at home. As Dr. Steinberg observed after a visit to the school: "Charity effectively broke down learning tasks that were overwhelming for Miguel, and using clear, articulate and well-executed ASL, she was consistently able to help Miguel understand receptively and respond with evidence that he could complete the tasks she set before him."

Charity described her experience with Miguel as follows: "Miguel's motivation to learn and do well in school caught my attention. After he helped me understand where he was coming from, I was able to show him strategies for dealing with classroom tasks and help him overcome his fear of failure. His self-esteem improved significantly because he no longer felt inferior."

Another important accommodation for Miguel was the availability of sensory strategies all day long, for example, "heavy work" such as arranging chairs before a group activity or tactile stimulation like the stretchy toy described above. Meeting Miguel's sensory needs helps him stay regulated, and thus ready for engagement and learning.

When Miguel was in first grade, the family decided to add medication to the mix of approaches used with him. This has proven beneficial, although not the mainstay of his progress. Miguel is less impulsive and more attentive, with the result being that he arrives at school more ready for learning. At the same time, without the support and accommodations, we would

not be seeing so much progress in development.

A continuing challenge is the need for constant coordination of the work of the multiple people involved in Miguel's school life—from teachers to therapists to ASL specialists. He benefits most when all of those people apply their skills in a consistent way, reinforcing the learning from one setting to another and emphasizing the practical application of language and socialization learning throughout his day.

Miguel at School Today

Since those early months of using the Floortime approach, Miguel's overall progress both at school and at home has been amazing. He is now happy much of the time, seems to derive real joy from being close to those he loves, tries hard to interact and regulate his actions, and his tantrums and disruptive behaviors are less frequent and shorter in duration. This progress shows that when families take the lead in Floortime, when schools focus their efforts on an approach like DIR, and when both actively collaborate, wonderful things can happen for a child with significant challenges. In Miguel's case:

- his atypical behaviors have come to be seen as unexpected rather than disruptive or intrusive;
- the frequency and intensity of his truly disruptive behaviors have decreased significantly;
- his level of engagement has greatly increased;
- he feels himself a true participant much of the day at school;
- his language is blossoming, albeit still significantly delayed for his age;
- his self-help skills and independence are increasing rapidly at home and at school; and

- his relationships are becoming deeper, with shared experiences and empathy increasingly evident.

Miguel is now in the third grade, getting ever further from the kindergarten where there are other children at his developmental level. He lags significantly behind his peers and has not proceeded up the developmental ladder in a fluid way, skipping important steps that contribute to a child's ability to use language and socialization in a practical context. Still, he is doing well and even thriving in some ways. His teacher, aide, and others who work with him directly are collaborating like never before, and the school's leadership is supportive. People enjoy Miguel, and that shows in the quality of their interactions with him. He's a handful and doing inclusion right (see sidebar) is a continuing challenge for any school. Still, Miguel gives something to the school, too. As Pat Hulsebosch, a parent of a former KDES student and a senior Gallaudet University faculty member says, "All too often it seems that children like Miguel are viewed for what they 'need,' what they take away from others—at home and at school—in terms of attention, time, resources, etc. We should also be looking at them in terms of what they add or contribute to our families and communities, and what we can do to enhance their contributions."

There are many factors in Miguel's progress, including our approach at home, the role of his big sister, and our good fortune in finding exceptional Gallaudet graduates to help out at home. But school is critical—from pre-school through high school we are looking at 16 years of growth and learning in an educational setting. So for us, while inclusion at a school for the deaf is an important principle, for Miguel, it's an imperative.

Inclusion at a School for the Deaf—A Parent's Perspective

"To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled."

~From the IDEA law defining "Least Restrictive Environment" or LRE

"It is within schools that children and adults learn some of the most basic lessons about who matters in the world ... it is only within inclusive schools that anyone can become a fully loving and competent human being and citizen. ... Inclusion is not a favor school systems do for students whom they perceive as "disabled," but a gift to our common humanity"

~From *Widening the Circle: The Power of Inclusive Classrooms*
by Mara Sapon-Shevin

Inclusion Makes Sense, But There are Challenges

Activist educators and parents have successfully argued that LRE when applied to deaf students can mean placement in a school that

is fully accessible through visual language, meaning a school for the deaf. This is now accepted practice. Not so well-received has been the argument that LRE for a deaf student with multiple disabilities must then mean that he or she gets to go to that same school for the deaf. Throughout the country there are states where the schools for the deaf prefer to educate students with multiple disabilities in separate classrooms or even on a separate campus from other deaf students, and there are school districts where a deaf child like Miguel is sent to a hearing program for multi-disabled children rather than a school for the deaf.

The questions raised about inclusion in schools for the deaf are similar to those encountered in public education in general: Will resources allocated to the special needs students take away from the "regular" students? Will those students slow down the learning for others? Wouldn't a student like Miguel be better off in a place where the staff is trained in dealing with his or her needs? Many who favor inclusion answer these questions with a resounding "NO," and there is a growing group of educators and parents who support this

perspective. What is needed is the engagement of all stakeholders in an open process of considering each of the objections and the potential benefits for all children of the inclusive approach. In the words of Sapon-Shevin, "Inclusion means engaging all members of the school community in explicit discussions of the value of inclusiveness." However, that discussion is just a starting point; to make it work, inclusion must be done right.

Deaf children with multiple disabilities need to go to school in a language-rich, visual learning environment with full-time exposure to ASL and deaf culture. In this way they are the same as all of their deaf peers. Only the schools for the deaf offer the possibility

- Coordination of educators and service providers in a way that enhances the student's opportunities for progress
- A qualified aide to provide 1:1 support to the student
- Strategies to support the student's development in sustaining interactions with peers; while his or her ability to relate to people may grow rapidly, for the most part it is adults who can adjust their communication styles and have the patience to successfully interact
- Language goals that focus on finite learning to fill gaps in the student's language base and encourage the everyday practical application of language



of providing such an environment. Still, in addition to the lack of broad support for the inclusion approach, there are practical challenges in successfully applying this model in schools for the deaf. Inclusion for a student like Miguel means 1:1 support for much of the school day, which may be a question of resources for the school. Not enough teachers of the deaf have training in educating multi-disabled students. Not enough professionals have training in deaf education in the kind of approaches that in the past have been seen as "alternative," such as DIR® and Floortime™. There is more training available for approaches that rely on behavioral training that are in use in school systems throughout the country. There is hope, however; Gallaudet University and colleges with deaf education departments are showing a growing interest in bilingual/bicultural deaf education, and in those settings there are opportunities for expanding the preparation of teachers in the inclusion approach.

Key Programmatic Elements

The ideal educational program for a student such as Miguel would include several elements that distinguish it from plans for students with less challenging needs. Among the key provisions:

- Identification of the student's interests and the utilization of those interests to work on academics
- Use of visual schedules and the time to discuss them with the student
- Flexibility on how the student participates (as opposed to if he or she participates)
- Use of sensory strategies throughout the day and breaks from sit-down classroom work as needed
- Careful consideration of student discipline (a child such as Miguel has frequent "unexpected" behaviors and the occasional disruptive behaviors; learning social skills must be approached through a variety of methods, from social story picture books, to role playing, to pretend play and recognition of good behavioral choices)

In addition to those elements listed above, a plan for the future, when the academic gap between the student and his or her classmates in an inclusive setting is likely to widen (the educational team will need to find ways to keep the student fully engaged and challenged

as the material and pace needed for the other students' academics increases), is also an important part of the educational program.

Schools for the Deaf are Well-Poised to Do Inclusion Right

In 2008 the Clerc Center adopted new strategic goals. Among them is the commitment to "provide leadership in the identification, evaluation, and dissemination of evidence-based instructional practices, strategies, and resources for deaf and hard of hearing students with disabilities." This is a welcome start in what should be a national dialogue around inclusion at schools for the deaf.



Additionally, deliberate discussions need to take place involving the school community of educators and parents about how an inclusive school setting is beneficial to schools.

The entire KDES program is "special education," with small class sizes and sensitivity to the individual needs of all students to a degree not possible in large public school settings. Each KDES student has an Individualized Education Program (IEP), so in some ways it's not as much of a stretch to get inclusion right there as it might be elsewhere, where at times "inclusion" might mean putting a student in a regular classroom with an aide to keep him or her busy. As Sapon-Shevin says in *Widening the Circle: The Power of Inclusive Classrooms*, "Inclusion offers us chances to rethink the teaching/learning process, recognizing that people learn in many different ways, and that education can be structured very differently." For schools like KDES and other schools for the deaf, that doesn't have to be such a radical notion.

Some accommodations are relatively easy to make. Once a school is committed to an inclusion approach, strategies do not necessarily have to stretch limited resources (e.g., the use of visual schedules and sensory activities)—and most often other students derive benefits

from those strategies indirectly.

Other resources may be less accessible regardless of the student's placement. Those include challenges in identifying, training, and supporting teachers of the deaf in the inclusion approach. For a hearing child with multiple disabilities, there are often alternatives to inclusion at the local public schools. The choices may not be great, and at times it may be hard to get the alternative program approved for a child, but often there are choices. For a deaf child, very few such choices exist around the country. So if the child clearly needs, as Miguel does, to be in a visual learning environment surrounded by people signing fluently in ASL, that means inclusion at a school for the deaf.

Making schools for the deaf inclusive settings for deaf students with disabilities is important for their all-around development. The consequences of disregarding this need may be severe. In the Spring/Summer 2008 issue of *Odyssey*, Dr. Steinberg says, "It is all about language and the opportunity to gain access to language. The deaf child who has an autistic spectrum disorder and is reliant on sign language may require additional adaptations to make communication and socialization accessible. Without this, the possibilities for social isolation are staggering."

Even if Miguel were hearing and we had a choice of a special needs school where all the children had challenges at least as severe as his, our family would probably not choose that option. Miguel clearly benefits from the communication and behavior modeling of all the people at KDES, from being part of a community of deaf children and deaf and signing hearing adults, and from being in school with his big sister, Wendy, for several years.

Miguel's experience at KDES shows it is possible to make inclusion at a school for the deaf work. Lori Rolnick, an occupational therapist at KDES and the former IEP coordinator, offers this perspective: "There is no doubt that from the beginning, creating an environment where Miguel could thrive was a challenge for both the school and the family. There were many long meetings that left us feeling frustrated and unresolved. Throughout this period, however, the family persisted and the school adjusted until finally we put in place some key accommodations and strategies which began to open the door to greater engagement and learning. Miguel today is a different child, and a testimony to what can happen when school and parents form a partnership that is truly in the best interest of the child." And, as Wendy says, "Many people ask this question: 'Is it challenging to have a brother like him?' The answer is yes, but it's not at all close to as challenging as it is for him."

References

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